



MessaGes

Myasthenia Gravis Association of Queensland Inc

JUNE 2013



Myasthenia Gravis Association of Qld Inc IN NO WAY endorses any products, medical procedures or medical practitioners mentioned. Articles are provided as a guide, and/or for information purposes only.

We take this opportunity to thank Queensland Health who by the provision of a grant, make the work of the Association and the publication of this Newsletter possible, and to those who take the effort to contribute to its success.

Myasthenia Gravis Association of Queensland Inc

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Neurologist
Founder Member, of Brisbane

PRESIDENT'S REPORT

Welcome,

We have a bit of good news regarding our funding from Queensland Health. As previously mentioned, our current triennial Service Agreement with QH is due to expire on 30 June 2013. Advice has been received from QH that they will extend the current Service Agreement for a further period of six months, i.e. until 31 December 2013 and that pro-rata funding will apply for that period. The question of further funding will, hopefully, be resolved prior to 31 December.

It would help our case for continued funding if members contacted their local State member of Parliament telling him/her of how the Association gives support to MG sufferers and their families and how withdrawal of the Queensland Health funding grant would impact on the Association's ability to provide that support.

The mid-year function was a great success and a report is inside this edition.

Don't forget to put Sunday 15 September in your diary for the Annual General Meeting at the Southern Cross Sports Club in Mt Gravatt. A Guest Speaker has been arranged and more details will appear in ensuing issues of MessaGes.

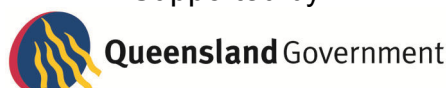
We are still looking for someone to take on the job of editor of MessaGes as the current editor, Graeme, wants to relinquish the job very shortly (he will still do the printing and distribution of the newsletter). We therefore plead with members to give serious thought to this matter as it is very important to keep the newsletter going as the main medium for keeping members up-to-date on what's happening in the MG world. If you need further information about the job, please contact Graeme on (07)32884484 or email him at graeme.peters2@bigpond.com

The basic equation for this situation is: **No editor = no newsletter.**

Take care

Anita

Supported by



PROJECTS UPDATE

Collecting data on sufferers of myasthenia gravis –

On Sunday 16th June, Dr Stefan Blum and Dr David Lee generously gave of their time to present to the Association members the results of the past months' work in analysing the survey data. Dr Lee had devoted his holiday break to the task and Dr Blum did the presentation, afterwards fielding many questions. His presentation focused on several demographics and two key issues in particular. The details of this are best watched when all current financial Category 'A' members are forwarded the DVD of the presentation. Most humbling was the comment from Dr Blum, that the results highlighted to-date will affect his understanding of the condition and his recommendations for patient management. Medical Journal Articles will be prepared over the coming months and will hopefully be published by Christmas. Several projects for further research have been discussed. During the event, a few members said they had chosen not to complete their survey as they felt their story was not of significance or the diagnosis was too recent to be valuable. Dr Blum was quick to reassure them that this is not the case. All stories and contact with sufferers is wanted. Please call if you need a replacement copy of your survey. Thank you again to everyone for being so supportive. The story of the survey continues, with more information and benefit set to follow.

'Exercise Effect in MG' Pilot Study –

EXERCISES AT HOME

The results of the Study are in the process of being fully documented and written-up formally and will then be available for the world to see.

We will advise when the MGAQ receives its copy and make it available to read to all interested members.

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SHIRLEY'S RECIPE

DATE SLICE

Ingredients:

2 cups SR flour	1 cup brown sugar
125g softened butter	1 cup finely chopped dates
1 egg, lightly beaten	1 cup milk

Method:

1. Combine SR flour, brown sugar. Rub in softened butter (this can be done in a blender).
2. Make the base - press half of the mixture into a lamington tray lined with baking paper.
3. Add dates, beaten egg and milk to remaining mixture.
4. Spread and press on top of base.
5. Bake in a moderate oven (180°C) for about 25 minutes or until cooked.

A businessman tells his friend that his company is looking for a new accountant. His friend asks, "Didn't your company hire a new accountant a few weeks ago?" The businessman replies, "That's the accountant we're looking for."

"You are a cheat!" shouted the prosecuting attorney to his opponent. "And you're a liar!" bellowed the defence attorney. Banging his gavel loudly, the judge interjected, "Now that both attorneys have been identified for the record, let's get on with the case."

CHAT LIST:

Each member of our Management Committee is happy to speak with you, while the following members, who include MG sufferers or their carers have offered to join our Chat List. If you have a need to have a yarn, particularly about how MG affects you, please ask if it is convenient to talk, and respect the privacy of those whom you call.

In the interests of one's privacy, we have not listed surnames. Do not be embarrassed by ringing a stranger and asking to speak to say, "Fred or Mary". If you wish to disclose your surname, that is your prerogative. Simply explain that you are a MYASTHENIC or a CARER.

The opinions expressed by the person you call are entirely those of that person. Care should be taken if following advice or suggestions presented and it is strongly recommended that the advice of your GP or Specialist is taken in all cases.

Remember there is also the FREECALL telephone number for Australia manned (or is it womanned?) by Shirley and is 1800 802 568. Please do not hesitate to call if you feel the need. If the 1800 802 568 is not answering, please leave a message and Shirley will get back to you as soon as practicable. Your call is valuable to us, so please do not hang up without leaving a message.

CHAT LIST – QUEENSLAND REGIONAL COORDINATORS

DONNA	0414397462	CAIRNS
CAROL	4773 7122	TOWNSVILLE
BILL	4954 1221	MACKAY
VACANT		ROCKHAMPTON
SHIRLEY	5443 1728	MAROOCHYDORE SUNSHINE COAST
VACANT		GOLD COAST
VACANT		BUNDABERG/WIDE BAY
VACANT		DARLING DOWNS

CHAT LIST – QUEENSLAND REGIONAL MEMBERS

KELLY	4728 4913	AITKENVALE
JOHN	4783 1556	AYR
YVONNE	4783 4643	AYR
MARK	4067 1784	BABINDA
LYNDA	4159 2890	BARGARA
JOHN	4959 5492	BAKERS CREEK
SARA	0422 109492	BLACK RIVER
HENRY	4982 6507	BLACKWATER
KELLY	4782 5542	BRANDON
PAMELA	4151 5499	BUNDABERG
SYDNEY	4051 6896	BUNGALOW
ROBYN	5520 4242	BURLEIGH HEADS
MOYRA	5576 4979	BURLEIGH WATERS
PATRICIA	5535 0274	BURLEIGH WATERS
JIM	0414241091	BURPENGARY EAST
DENISE	4788 0798	BUSHLAND BEACH
DAVID	4053 2291	CAIRNS
RON / HELEN	4051 3286	CAIRNS
OWEN	4742 1190	CLONCURRY
BARRY	5483 1783	CURRA
GLORIA	5534 2669	CURRUMBIN
MELISSA	4662 3337	DALBY
GARTH	4973 7983	GLADSTONE
ELIZABETH	4936 2410	GLENLEE
LILLIAN	49334281	GRACEMERE
KARLIENE	0432431591	HERVEY BAY
SHIRLEY	4128 3596	HERVEY BAY
ANGELA	0427752956	HOPE ISLAND
JAMES / ROSEMARY	5530 1558	HOPE ISLAND
SERAFINA	4751 6415	JENSEN

CHRISTOPHER	0412456439	LABRADOR
JUDIE	0439 461288	MACKAY
TERRY	5494 2470	MALENY
MAUREEN	5572 7993	MERMAID BEACH
ROBERT	5492 9754	MOOLOOLAH VALLEY
KATREN	0418778082	MONTEREY KEYS
JOY	4165 4647	MUNDUBERRA
BROOKE	0404720807	NAMBOUR
ALEX (BROOKE'S CARER)	0420858386	NAMBOUR
KEITH	5441 7236	COES CREEK, NAMBOUR
MICHAEL	5545 2802	NORTH TAMBORINE
DAVID	5474 5534	NOOSA
MARLENE	5447 4986	NOOSA HEADS
SHARON	4151 7661	NORTH BUNDABERG
MAUREEN	0411331258	PACIFIC PINES
JUNE	0409636467	PALM BEACH
SCOTT	5448 1749	PEREGIAN BEACH
TOM / SCOTIA	4693 3730	PITTSWORTH
BILL / COLLEEN	4926 2410	ROCKHAMPTON
DONALD	5563 7207	RUNAWAY BAY
HELEN	5445 4853	SUNSHINE COAST
BERNIE	JoyPaul28 *	TEWANTIN
BETTY	4635 6270	TOOWOOMBA
DIANNE	4638 8447	TOOWOOMBA
HEATHER	4728 7550	TOWNSVILLE
LUCY	0418879801	TOWNSVILLE
JO	4723 8721	TOWNSVILLE
ANNE	0487305153	TRINITY BEACH
VALMA	4068 0702	TULLY
KATHLEEN	5573 0439	UPPER COOMERA
RAJKO	5556 0639	UPPER COOMERA
ANDREA	5486 7671	WOLVI
JAN	5493 4441	WURTULLA
SANDY	0458980667	YANDINA
PERLA	4939 2724	YEPPOON
IAN	4623 5169	YULEBAR

Please note that * indicates that this member is available via the VOIP Skype facility on a computer

AMENDMENT TO CAIRNS MEETING

The meeting of Cairns Regional members which was scheduled for Saturday June 15 2013 has now been rescheduled for Saturday June 29 2013 at the Cairns RSL Board Room commencing at 10:00am.

MORE OF BARRY'S LINKS OF INTEREST

The following links to item of interest regarding MG have been submitted by member Barry who browses the Internet looking for such items. The committee thanks Barry for his interest and efforts.

Getting diagnosed:

<http://fightmg.blogspot.no/p/getting-diagnosed.html>

* * * * *

"Don't be so humble - you are not that great."

- Golda Meir (1898-1978) to a visiting diplomat

KEEP YOUR BRAIN ACTIVE WITH THE TRIVIA QUIZ

The quiz is back - Here are some questions for you to try on a cold night this winter. (Answers are at bottom of this page)

1. Gallifrey is the home planet for which science-fiction character?
2. Hartford is the capital of which USA state?
3. What is the collective noun for a group of flamingoes?
4. Traditionally, which wedding anniversary does copper celebrate?
5. Who wrote *The Canterbury Tales*?
6. Is a 'nautical mile' shorter or longer than a 'mile'?
7. What was the name of the Lone Ranger's horse?
8. In which Australian state or territory is Winnaleah?
9. How many moons does Venus have?
10. Who was the second USA President?
11. What is the name of Queen Elizabeth's horse which won this year's Gold Cup at Royal Ascot races?
12. How many members sit in in Australia's House of Representatives?
13. What is the middle (4th) colour of the spectrum?
14. Which is the only Central American country with English as its official language ?
15. Who wrote the historical novel '*Last of the Mohicans*'?
16. What is the capital of Greenland?
17. Olympic women's Decathlon starts with which event?
18. The *pinna* is found where on the human body?
19. '*Out on a Limb*' is an autobiographical book of which actress?
20. What is the name of the Japanese parliament?

Answers: 1) Dr Who; 2) Connecticut; 3) Stand; 4) Seventh; 5) Geoffrey Chaucer; 6) Longer – approx. 1.1508 miles; 7) Silver; 8) Tasmania; 9) None; 10) John Adams; 11) Estimate; 12) 150; 13) Green; 14) Belize; 15) James Fenimore Cooper; 16) Nuuk; 17) 100 metres hurdles; 18) Ear; 19) Shirley MacLaine; 20) Diet.

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"A people that values its privileges above its principles soon loses both."

- Dwight D. Eisenhower (1890-1969), Inaugural Address, January 20, 1953

MID – YEAR FUNCTION HELD ON SUNDAY 16 JUNE 2013



Dr. Blum cutting the 'MG Awareness Month' cake

The mid-year function held at the Southern Cross Sports Club, Mt. Gravatt, on Sunday 16 June 2013 was a resounding success.

The attendance was 48 members, partners and prospective members. It was very pleasing to see so many of our recent new members at the function.

The presentation by Dr Blum entitled 'Some Interesting Results from the MG Survey' was very well received and led to many varied and intelligent questions being put to Dr Blum during the Q & A Session.

One of Dr Blum's confreres on the Study, Dr David Lee, attended and it is worth noting that Dr. Lee spent 4 weeks

of his annual leave going through the survey data. Actions such as Dr. Lee's certainly indicate the importance of the survey and the Association is so very appreciative of both Dr. Blum's and Dr. Lee's efforts.

One of the most interesting results from the survey is that Dr Blum indicated that neurologists may have to change the way in which they treat some patients with MG (more detail is on the DVD of the presentation).

Treasurer Susan White gave the Vote of Thanks for Dr. Blum, presented him with a Certificate of Appreciation and a small gift, and then asked Dr Blum to cut the 'MG Awareness Month cake' (June is MG Awareness month in the USA) which was then distributed to all present to enjoy.

About 30 people stayed for lunch, as did Dr Blum and Dr Lee.

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NOMINATIONS FOR MANAGEMENT COMMITTEE FOR 2013/2014

The following nominations have been received, and accepted by the nominees, for positions on the MGAQ Management Committee:

President	Anita Jackson
Vice-President	John Noble
Treasurer	Susan White
Secretary	Carol Buchanan
Committee Members	Shirley Johnston, Bill Synnot

There was no nomination received for the remaining Committee Member position and in accordance with the MGAQ Constitution, nominations for this position will be called for from the floor at the Annual General Meeting.

* * * * *

IT'S MEMBERSHIP SUBSCRIPTION RENEWAL TIME

It's that time of the year again when Membership Subscriptions for the financial year 2013/2014 are due. Membership Fees are the same as last year.

The envelope in which this notice was enclosed will advise you when your membership expires. If you look along the top line you should see "YOUR NAME" followed by some figures in smaller print than your address. If you receive the newsletter by email and are unsure whether or not you are currently financial, please ring our 1800 802 568 freecall number to enquire.

The majority of members will have 6/13 which tells you (and us) that you are financial to 30 June 2013. Others may show 6/14 or even 6/15 to indicate they have saved time and postage by paying in advance. However, there are others whose envelopes still show 6/12, 6/11, etc. and we continue to send our newsletter to these unfinancial members because we do not know what they want. **If you are unfinancial, please take a minute to ring on the FREE call number, 1800 802 568 and advise whether or not you wish to retain your membership and receive "MessaGes".**

LIFE MEMBERS and PAID-UP LIFE MEMBERS do not pay further subscriptions.

We are also giving you the option of paying your subscription directly into our bank account. Our bank details are:

BANK: Bank of Queensland
BSB: 124 032 **ACCOUNT NUMBER:** 10263772
ACCOUNT NAME: Myasthenia Gravis Association of Qld Inc.
REFERENCE: Your Name & Initials

If you use the direct deposit method, it would help if you could email us at info@mgaq.org.au to advise that you have paid directly into our bank account and the date of the transaction. This will assist the Treasurer in reconciling with the Bank Statement.

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Tear off along this line

If you wish to pay by cheque or Money Order, please use the following form and forward to:

The Myasthenia Gravis Association of Queensland Inc.
PO Box 16
MT GRAVATT Qld 4122

Herewith please find my cheque / money order / cash for the sum of \$_____ being annual subscription \$_____ and/or Donation \$_____:

NAME: _____ **Category A – Myasthenic \$15**
Category E – Supporter \$15

ADDRESS: _____

AND FOR: _____ **Category D – Carer \$5**

ADDRESS: _____

Your receipt will be forwarded to you with the next available issue of "MessaGes" following receipt of your payment. If you do not receive your receipt, please ring us on the toll free number 1800 802 568. We thank you in anticipation of you renewing your membership.
